

CONSULTATION QUESTIONS

Are you responding *primarily* as a data custodian, data user or data subject? (We recognise all people are data subjects and many organisations act as data guardians and data users, but please tick only one box)

- Data Custodian
- Data User (e.g. researcher)
- Data Subject (e.g. member of the public or group representing citizens)

1. Are there any benefits of data linkage for statistical and research purposes that are not sufficiently described here?

Yes, there are further benefits No, the benefits are described fully

If you ticked 'yes', please describe the further benefits of data linkage for statistical and research purposes.

Comments

2. Are there challenges or barriers preventing more effective and efficient data linkages for statistical and research purposes taking place that are not sufficiently described here?

Yes, there are further challenges No, the challenges have been identified

If you ticked 'yes', please describe the challenges or barriers.

Lack of awareness of the availability of datasets which can be linked and the potential these datasets offer. For example, awareness of health-data linkage is relatively high and numerous examples exist of research undertaken using these data. Thus the capabilities of these data are quite widely known. This is perhaps less so for data held by DWP or HMRC. Before overcoming the practical challenges and barriers (like secure exchange, analytical capacity) it will be necessary to ensure that organisations and individuals know enough about what data could be made available via linkage and how that linked dataset may be used to answer research questions in order that, ultimately, they use it.

3. Are the guiding principles sufficient and appropriate? Please explain your answer fully and make suggestions for improvement.

Yes, they are sufficient and appropriate No, they are not

Please explain your answer fully and make suggestions for improvement.

Comments

4a. Are the objectives set out for a Privacy Advisory Service in Section 3c the right ones?

Yes, the objectives are right

No, they are not

Please explain your answer fully and make suggestions for improvement.

4b. Do you wish to be consulted on firmer proposals for a Privacy Advisory service as and when they are developed?

Yes No

5a. Are the functions that will be led by the National Data Linkage Centre set out in section 3d the right ones?

Yes, they are the right functions

No, they are not

Please explain your answer fully and make suggestions for improvement.

The functions suggested do appear to be right for what the National Data Linkage Centre is aiming to achieve. However, some of these functions already exist within key organisations undertaking linkage so the proposal for a National Data Linkage Centre itself raised a number of questions for us. We accept that further development of proposals for the Centre is planned, but thought it was worth raising these queries at this stage.

Will the Centre remove/replace data linkage and exchange services/processes that currently operate within data custodian organisations such as ISD and ScotXed, or will it seek to provide the service only for organisations where there is no current linkage capability/experience? Is the Centre going to 'pool' individuals with relevant linkage experience from the key organisations and/or provide additional, central, non-affiliated resource?

At the beginning of the consultation document you have provided an example of data linkage for research and statistical purposes, how would this same scenario operate under the National Data Linkage Centre – starting from the initial proposal to undertake linkage of the two datasets?

5b. Do you wish to be consulted on firmer proposals for a National Data Linkage Centre as and when they are developed?

Yes No